

Social care and older people with chronic kidney disease: a mixed-method narrative review

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SOCIAL CARE AND OLDER PEOPLE WITH CHRONIC KIDNEY DISEASE - A MIXED-METHOD NARRATIVE REVIEW

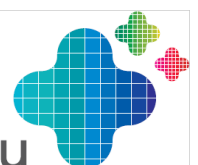


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Uned Ymchwil Arennol Cymru
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FOREWORD

From Joanne Popham, founder Paul Popham Fund:

Here at the Paul Popham Fund we work to support older people with CKD through a variety of services and **recognise the pressing need to learn more about how older people in Wales receive social care** so that we can use this information to enhance our service provision and focus on improving areas with identified gaps. We can only do this with good evidence.

We are so pleased that Bangor University has undertaken this review. **With the number of older people with CKD and related comorbidities**



expected to increase significantly by 2020, we need to know more about what works now and for whom in order to plan appropriately to meet the social care needs of our stakeholders now and in the future.

But it is also clear from the evidence in this review that **much more research is needed to gain an adequate knowledge and understanding of the social care needs of older people with CKD.** Professor Jane Noyes and her team have done some crucial work to highlight gaps in key areas for further investigation.

We hope this review will encourage researchers and health care professionals to engage in more depth with social care research and to take on some of the areas identified to improve social care for older people with CKD in Wales.

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Source: flickr.com

Summary

Chronic Kidney Disease (CKD) is a long-term condition. Older people living with CKD commonly have one or more additional diseases or disorders, which means that their health care is particularly complex. They are also likely to have increasing needs for social care over time.

This review describes the current state of research on social care for older people with CKD.

Key findings:

- There was a dearth of published research which provided any evidence on social care. Of the 7769 abstracts and titles identified only 36 papers from 32 studies provided any evidence on social care, and much of this evidence was not the main focus of the study.
- Research on older people with CKD is still predominantly led by medical or health-related professionals: Only one study had a primary social care focus and was carried out by social care professionals.
- We found no examples of older people's views or experiences of accessing and receiving social care interventions or services.
- We identified nine overall social care research topics for older people with CKD, which need further research.
- The social care needs identified in the evidence were extensive due to the multiple co-morbidities of living with CKD over a prolonged time.
- Renal clinicians name the lack of social care services as an influential factor regarding health outcomes, including quality of life.



Professor Jane Noyes

Professor in Health & Social Services (Research & Child Health)

Bangor University

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PHOTO ILLUSTRATION/THINKSTOCK

Source: neurowiki2014.wikidot.com

INTRODUCTION

Rising numbers of older people are diagnosed with chronic kidney disease (CKD) (McIntyre et al. 2012) or end-stage kidney disease (ESKD) (Namiki et al. 2010). Diagnosed kidney disease and the associated problems encountered by older people are leading to new challenges for social care. There have been no previous reviews conducted that look at social care and older people with kidney disease. **The purpose of the current review is to establish what is known about social care needs, and how services are experienced by key stakeholders.** This paper reports the review findings and highlights the significant gaps and opportunities for subsequent multi-disciplinary and social care led research.

Aim. The review addressed two questions:

- What are the social care needs of older people with kidney disease?
- What are older people's and other key stakeholders' views and experiences of accessing and receiving social care services?

Methods:

- a mixed-method narrative review to aggregate evidence from quantitative and qualitative studies
- independent review processes: second-checked and agreed by consensus

Search strategy

(The search strategy is outlined in Appendix 1). The following databases were searched:

- Cinahl,
- NICE Evidence,
- Social Care Online,
- Cochrane/Campbell,
- ASSIA,
- PubMed,
- Hand search: Journal of Nephrology Social Work.



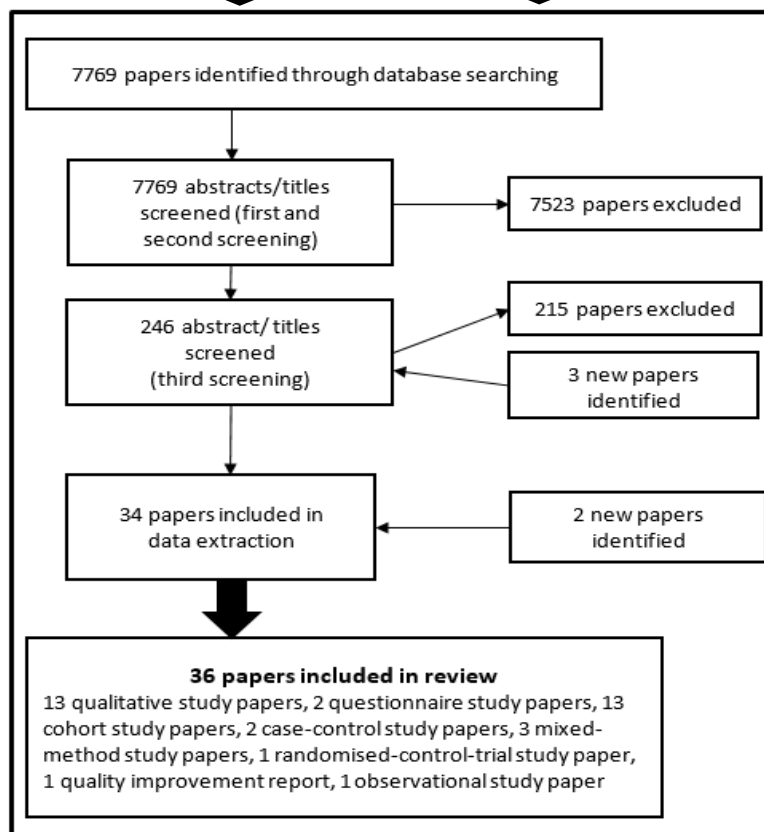
Study screening methods

Electronic database searching produced 7769 documents for initial screening. Paper titles were collated and de-duplicated using Mendeley bibliographic software (<https://www.mendeley.com>). Titles, and then abstracts were screened against the inclusion/exclusion criteria by the research team. A further two studies were identified through different sources at the final stages. The majority of studies were excluded leaving only 32 studies resulting in 36 papers that addressed the research questions and fitted inclusion criteria. Of these 36 papers: 6 were in the USA, 13 in the UK, 3 in Australia, 2 in Sweden, 2 in Norway, 6 in Canada, 1 in France, 1 in the Netherlands, 1 in Finland, and 1 transnational study in USA, Brazil, Italy, Germany and Japan. The studies varied in research methods, design, length and participants (Figure 1).

INCLUSION/EXCLUSION CRITERIA

Age range:	older people with CKD >65 and/or studies which included some patients >65 if the focus of the paper was primarily on older people over 65 years and/or if there was a section on older people >65 years
Health condition:	kidney disease or any renal problem: patients (with or without comorbidities) with kidney disease, including renal failure, dialysis, renal transplant etc.
Aspects regarding social care:	any type of need or social support for self-care at home; needs and available supports related to wellbeing, nutrition, diet, cooking, exercise, isolation, social occupation; community support, shopping, welfare benefits, housing and adaptation, transport, support for continued employment, families, carers etc. holidays, respite, palliative care etc.; inclusion of any needs/services at the social care and health interface – such as education and support provided by kidney outreach nurses employed by health teams
Service support:	e.g. financial support or other input or resources provided by the state and/or families, carers, third sector, paid or voluntary
Care setting:	families or carers looking after the older person with CKD and their needs
Perspective:	patients, families, carers, professionals, clinical, medical and academic
Study type:	any (qualitative, quantitative, and mixed method)
Patient setting:	any: community; home, alternative home; any form of supported living residential or day care; includes hospital or hospital alternatives (e.g. day care) as older people are frequently stuck in hospital as their social care needs are not yet addressed at home etc.
Date range:	studies from 2006 onwards until August 2016
Language:	English language studies only
Countries:	high income country context only

FLOW OF PAPERS IN THE REVIEW (Fig. 1)



DATA EXTRACTION AND SYNTHESIS

A specific approach to data extraction and synthesis was required as the majority of the 36 included studies were medically focussed and led from a clinical and not social care perspective. **Only one study had a primary social care focus and was carried out by social care professionals.** The primary research questions did not directly map onto to our review questions and we had to develop a synthesis approach that only extracted highly selected evidence that was helpful in answering our review questions. The primary research design and focus was therefore of less interest than the identification of social care needs and experiences. In almost all studies, the social care needs of older people were mentioned peripherally and most often in relation to compliance with medical treatment.

Whilst including quantitative, qualitative and mixed-method studies, we were only interested in the reporting of social care needs and experiences and this evidence tended to be reported in a narrative form and was often drawn from the researcher interpretations of their results. An *a priori* framework was developed to identify index codes relating to the social care needs and experiences of older people with chronic kidney disease.

Using NVivo software the text of each primary study was indexed, by at least two review authors, using the codes relating to the themes and sub-themes of the thematic framework. We extracted evidence relating to social care from the primary studies to determine common social care needs and then grouped the studies with common themes.

Use of tables to juxtapose quantitative and qualitative evidence enabled the team to compare the findings of studies across different themes and sub-themes and to compare the findings of different studies for each theme (Oliver et al. 2005). The resultant level of synthesis was however low. Studies could be grouped and reported in a narrative summary. There was insufficient commonality between studies to undertake a higher level of synthesis to come up with new interpretations.

FINDINGS

We found no evidence on key stakeholder views or experiences of accessing and receiving social care interventions or services. Reported social care needs and associated issues are summarised under nine themes:

- **Common social care needs**
- **Social care, wellbeing and quality of life**
- **The family as providers of social care for older people with CKD**
- **Lifestyle interventions with social care components**
- **Gender, CKD, older people and the implications for social care**
- **Education as a potential mediator for accessing social care**
- **Integrated health and social care**
- **Self-management and implications for social care**
- **Social care as a neglected element of end of life care**

Common social care needs

Remaining at home and keeping things as normal as possible were paramount to many participants across a variety of studies (Maaroufi et al. 2013, Nitsch et al. 2011). The feeling of losing 'control' of their lives was evident. **Examples of the common social care needs of older people with CKD and often multiple comorbidities included; at home support for domestic and personal care, support with taking medications at home and completing home treatments such as dialysis, accessible transport systems, welfare and housing support, help with renal diet and exercise regimes, counselling to underpin decision-making, and general wellbeing support, social integration and avoidance of loneliness and social isolation, age appropriate social events and support for family members and unpaid carers.** Most of these social

needs were described in the background or discussion sections of the research studies and articulated as being commonly unmet, which impacted on the health outcomes that were the primary interest.



Source: devozine.upperroom.org

Social care, wellbeing and quality of life

Three studies looked at coping with CKD, difficulties in performing tasks of daily life, and of the influence of power structures in dialysis care relationships (Llewellyn et al. 2014, Barrett Bowling et al. 2011, Aasen et al. 2011a).

Llewellyn et al. (2014) undertook a qualitative discourse analysis which showed that older people with kidney disease adopt various coping mechanisms in the face of chronic illness and associated comorbidities and applied specific narratives (including denial or acceptance) to deal with the burden of disease that would make it easier to manage the intrusion in their daily routine. **Participants either framed CKD and its comorbidities as part of old age, tried to relate it to their experiences with previous illnesses or chose a form of treatment that would create (at least in their minds) the least disruption in their daily lives.** These findings suggest that an important part of social care for older people is not only support in accepting a severe chronic illness like CKD, but also support in adopting appropriate coping mechanisms to contain the impact of CKD on familiar life styles and individual stories as much as possible.

Lack of integration of social care professionals in the interactions of health care professionals and patients

Aasen et al. (2011a) investigated the area of the decision-making process and patient-health care professionals relations and **found out that the less patients were able to participate and/or felt that they were subjected to a power gap with professionals, the more they suffered from anxiety and depression.** Patients expressed feelings of powerlessness, loss of autonomy and freedom, and that decisions were made over their heads. The study suggests that a change in the social practice and attitude towards patient participation would considerably improve patient wellbeing. This could involve an increased degree of information and dialogue with patients and a stronger participation in the decision-making-process, especially if treatment choices can have a considerable impact on patients' social life and independence. Additionally, structural changes can improve the patients' wellbeing for example, if nurses are allowed more time to communicate with patients regarding their treatment and the daily health care routines affecting them. Importantly, the role of the renal social worker was largely absent from the analysis or discussion.

CKD as an indicator of age related comorbidities and the need for social care

Barrett Bowling et al. (2011) showed that CKD in old age is closely connected to functional decline regarding both the so called instrumental activities of daily living (IADL) and the basic activities of daily living (BADL). CKD itself can be a predictor of declining functional impairment, but also the degree of the severity of the current CKD stage or the impact of complex comorbidities associated with CKD. Monitoring the relation between age development and corresponding status of CKD can help social care services anticipating and monitoring potential changing needs of daily support for community-dwelling older people as well as adjusting the social care needs appropriately to the current stage of functional impairment. Additionally, the study indicated that depression and cognitive impairment were also major issues for older people with CKD that will require the input of appropriate social care services.



The family as providers of social care for older people with CKD

The sense of burden on friends and family that patients described lead to concealment of their condition so that for some patients the involvement of their families was delayed (Walker et al. 2011). Several studies dealt with the involvement of families and their perspectives. For example, the experiences of family carers, their inclusion in decision-making, but also the implications of power relationships and hierarchies were major issues.

Axelsson et al. (2015) explored the experiences of close relatives of severely ill family members. **Caring for a severely ill family member can cause considerable disruptions in life and the more the patient deteriorates and becomes more dependent on family support, creates a considerable emotional strain to family members.** The findings identified the importance of communication and involvement of relatives, but also the appreciation of acknowledgement, collaboration, and trust. Social care can intervene to offer psychological support to strained family members, but also mediate between relatives, their needs and the interaction with the health care professionals. Simultaneously, support services can also help to provide services that relieve burdened families, for example in the form of respite care.

Aasen et al. (2011b) explored family members and their perceived participation in the haemodialysis treatment of older people. They identified a few issues especially regarding the relationship between relatives and the health care team. Among these problems were complaints about a lack of inclusion and participation in patient care, a lack of recognition of relatives' experiences and knowledge of this by the professionals and the feeling of being overlooked and forgotten. **Family members also felt excluded from relevant information regarding the health condition of the patient.** Support services can help identify potential barriers regarding the involvement of family members. As part of the process to overcome alleged power hierarchies in the relationship between family-health care professionals; appropriate social services could help facilitate the participation and communication between relatives and the health care team and provide the family with crucial information and better understanding regarding the health condition of the elderly relative and ongoing treatment processes.



Source: commons.wikimedia.org

Oliver et al. (2010) explored the use of peritoneal dialysis (PD) for elderly people in their homes. The study found that **older patients tend to use less PD, because of increasing barriers to self-care and of the dependency on available family support.** Even when home care was available, the option of having family members around to help with dialysis made a big difference in patient choice. However, since utilisation of PD supports a more independent life style for patients with kidney disease and is also more cost-effective, support services could facilitate the use of PD, if older people without family support could gain access to adequate care. Sufficient home care that ensured safe application of PD and strengthened confidence in elderly patients was one of the key issues for support services in PD care.

Some gaps detected in these studies were a strong focus on frail elderly patients and their family relations, which might have left out other groups of older people, as well as a still under-researched understanding of the dynamics between family and patient, regarding the issue of patient autonomy or treatment decisions (Aasen et al. 2011b, Oliver et al. 2010). At the same time there is also the possibility that patients face barriers, which are not identified by everyday practice of multi-disciplinary teams. Bias in judgment that might influence treatment practice and decision-making by health care professionals (Oliver et al. 2010).

Lifestyle interventions with social care components

Li et al. (2007) implemented an intervention designed to facilitate rehabilitation measures for older patients on dialysis with functional limitations. Older patients were enabled to attend geriatric rehabilitation that allowed them to go back to their own homes after acute hospitalisation or acute functional loss. The study points out that adjusting rehabilitation to the life situation of the patients, for example daily but shorter and less exhausting dialysis sessions, has a considerable impact on the quality of life and independence of elderly patients. Patients had more energy in daily life, were less bound to dietary requirements and less prone to referrals to care institutions. At the same time mutual education between health care professionals showed positive influence on the rehabilitation process as well. However, the authors made clear, that there was still very limited research on the rehabilitation of older people. Previous studies focused on younger patients, but there is still a lack of insight on appropriate rehabilitation measures for older people with CKD.

Gender, CKD and older people and the implications for social care

Nitsch et al.'s (2011) study deals with gender-related differences among older people with CKD who are 75 years or older. They found that differences in the estimated glomerular filtration rate (eGFR) had a significant impact on the quality of life among men and women.

This could mean different degrees of mobility or body care among men and women, but also within groups of men or women with different levels of eGFR. The study suggests that the effects of CKD are gender-specific and that the level of social care patients' needs can be predicted by and adjusted to their current stage of CKD and its associated eGFR.



Education as a potential mediator for accessing social care

Education was also broadly defined as participation, decision-making, information, knowledge sharing and educational interventions. An important issue was the lack of education, information and understanding that patients as well as their relatives experienced with their illness (Maaroufi et al. 2013, Llewelyn et al. 2014, Axelsson et al. 2012, Axelsson et al. 2015, Aasen et al. 2012, Aasen et al. 2012, McIntyre et al. 2012, Moustakas et al. 2015, Tonkin et al. 2015). **A large number of patients with CKD were unaware of their condition despite being on the CKD register** (McIntyre et al. 2012). Older people had a range of coping mechanisms to deal with their illness, a prominent one (as mentioned above) being denial of illness and symptoms. However, no qualitative in-depth studies have been conducted to learn about how older people felt psychologically when they began having symptoms.

Horigan et al. (2013) found that older people felt that they had not received any information on how dialysis would make them feel emotionally, or appropriate social care interventions to enable them to adjust. There is also little evidence on how dialysis did make patients feel. The issue of patients not accepting their symptoms of CKD and instead blaming them on old age, could influence their care plan decisions, meaning that they did not necessarily choose the care plan that was best for them at the time. Additionally, these patients are likely to have multiple co-morbidities. Walker et al. (2011) **found that additional illnesses entering the lives of those already touched by illness are less likely to trigger a different narrative or raise concerns about their changing health and symptoms** (Llewelyn et al. 2014).

Education and decision-making

Maaroufi et al. (2013), Visser et al. (2009) provided different aspects of how participation and inclusive decision-making could be achieved. All three studies discussed the significance of patient involvement in treatment choice and decision-making, however, they show that this is still limited due to the neglect or underestimation of home-based treatment or a lack of research on the treatment options. Therefore, **a lack of options or access to vital information restricts the possibility of the patients to make an informed choice** (Maaroufi et al. 2013 and Carson et al. 2009). Additionally, patients' considerations and their ideas on quality of life need more research to understand why they accept or decline certain treatment options and access to social care (Visser et al. 2009).

Maaroufi et al. (2013) aimed to find out how informed choice would influence treatment preferences regarding dialysis options. They found a tendency among older people, especially women, to opt for PD in their own homes, when informed about pre-dialysis. The main arguments that influenced the decision-making were the impact the treatment had on the quality of life (instead of increasing life expectancy) and the degree of autonomy that let patients keep up their familiar life style. The study supported the implementation of informed choice in the decision-making process to avoid treatment mismatches and respect patients' preferences, but also more education among health care professionals regarding the inclusion of patient participation when choosing appropriate treatment options.

Visser et al. (2009) suggest that decisions on treatment choice should not solely be based on medical grounds, but also include patients' values, beliefs, and feelings towards life, suffering and death. The researchers interviewed older people with CKD who were about to decide whether to initiate dialysis. They found that the criteria mentioned above and the expected difficulties to fit the treatment into their lives had a decisive influence on decision-making. Besides a recommendation for more patient participation the studies also suggest more transparency on patient education by physicians. During the study it remained unclear what type and amount of information was communicated to the patient and how this affected decision making consequently.



Source: nurseregistry.wordpress.com

Education and non-dialysis end of life treatment options

Carson et al. (2009) showed that allocation of social care, the possibility of comprehensive patient education, and well-researched knowledge on applicable treatment options go hand in hand. The study discusses maximum conservative management (MCM) as an alternative to dialysis for older patients whose life expectancy is limited. According to their findings, dialysis treatment can lead to medicalisation and hospitalisation, therefore, does not per se improve patients' quality of life or is in their best interest. They stress the importance of patient choice in decision-making and support multidisciplinary MCM as a viable alternative that can ensure survival for a significant period as well. However, the authors admit that currently there is still very little information available on non-dialysis treatment for patients with end-stage renal disease (ESRD), which makes it difficult to provide accurate information regarding treatment choice at this point.

Tonkin-Crine et al. (2015) investigated how the level of information and patients' beliefs about dialysis treatment options influence decision-making. According to their findings these beliefs seemed to rely on the information provided by renal staff, particularly whether patients were aware of conservative management as an option. For example, a lack of lay-expert dialogue regarding illness trajectory and advanced care planning had led some patients



initially to prefer conservative management, but then changed their decision to dialysis treatment when they became unwell. There were also different beliefs among patients regarding the prospected life expectancy whether on conservative management or on dialysis/pre-dialysis and the effect on their quality of life. The validity of the information given also depended on the fact, if a renal unit supported an established conservative management pathway and had more experience with this treatment option. Altogether, patient education across several renal units had proven to be very inconsistent and the authors suggest the development of evidence - and information-based decision aids that could help support staff promoting informed choice impartially.

Similar to the study above, Moustakas et al.'s (2015) investigation also found that information on supportive care for older patients with advanced chronic kidney disease (ACKD) can be very inconsistent, especially, if there is no formal renal supportive care programme implemented. The findings show that older people place high value on their quality of life, meaning maintaining independence as much as possible and spending time at home with their families around them. Therefore, dialysis treatment is often perceived as intrusive to personal life, but at the same time there is often only inconsistent, non-systematic or unplanned information on supportive care alternatives available to older people and their relatives. Additionally, memory loss and cognitive impairment in combination with changing health care staff can have a negative effect on the information recollected as well. To sum up, the study suggested to conduct cognitive assessments for appropriate education provision, but also to establish formal renal support services for more consistent and reliable patient information.



Source: chillopedia.com

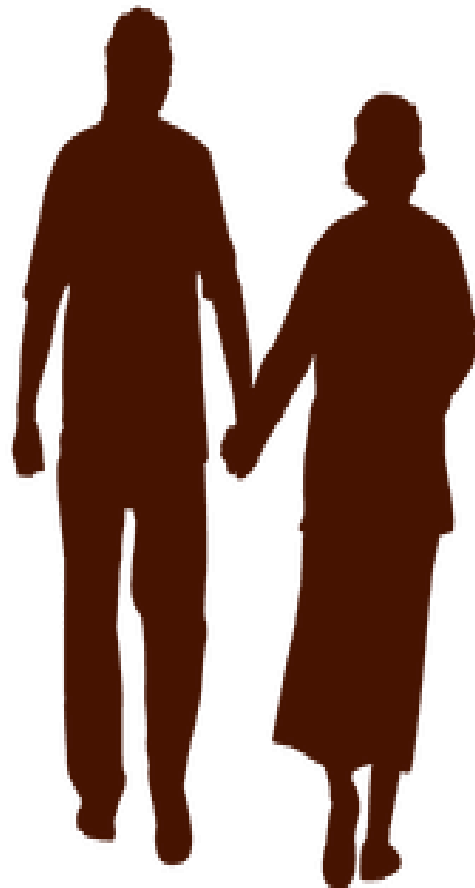
Rantanen et al. (2008) conducted a patient-focused study that looked into the knowledge expectations of people with CKD. According to their findings the older patients among their participants had a stronger focus on experiential knowledge. This included the wish for a contact person to talk to about feelings regarding their illness or counselling on how to take advantage of previous hospital experiences in order to cope better with CKD. As a consequence of these findings the researchers suggest a stronger establishment of conversational therapy for retired patients.

Bristowe et al. (2014) looked closer at the role of professionals and their communication skills. Health care professionals face an increasing number of frail and elderly renal patients with a deteriorating condition, but apparently, they feel unprepared for discussions in the form of Advance Care Planning (ACP) on patients' preferences and future care. Identified reasons for this issue on the side of the professionals were long established therapeutic relations and, thus, a reluctance to create distress as well as a lack of communication training. The authors investigated the piloting of the Renal specific Advanced Communication Training (REACT) for health care staff to improve ACP discussions. The training was evaluated as a feasible method to address communication training needs of renal professionals and as potentially improving professionals' confidence when discussing end of life issues. Therefore, the findings suggest that **more communication training tailored to the challenges of renal professionals might strongly improve patient-professional-communication and patient education.**

Lack of appropriate communication and education is also at the centre of McIntyre et al.'s (2012) study. When looking at 1741 clinically assessed older patients in primary care in the UK, the authors **found out that 41% of the patients were not aware of their CKD diagnosis, even if their GP had registered them on a CKD register.** According to this study, particularly patients who were female, 75 years or older and had no formal educational qualifications showed a lack of awareness of their condition. That means patient education should focus particularly on these groups of patients and newly identified patients with CKD should receive information and be offered further information as well. Since the attested awareness of the CKD diagnosis tended to be only superficial, the authors suggest further in-depth research on the level of CKD awareness and knowledge.

Harwood et al. (2009) looked at old age and CKD from a different perspective. They investigated stressors related to patients with CKD and found out that fatigue, sleep problems, peripheral neuropathy, muscle cramps and restless legs were the five most frequently reported stressors in patients with CKD. When looking at coping strategies concerning negative effects of CKD it turned out that optimism was named the most preferred coping strategy by all participants, regardless of age. However, **older people tended to be less affected by CKD-related stressors and less stressed about the unknown and uncontrollable, because they were able to draw from previous experiences and to use familiar, already successful coping mechanisms.** This suggests that social care services, who support older people with negative effects of their condition, should look at past experiences and help patients to develop coping strategies that build on previously successful mechanisms.

Pruchno et al.'s (2006) account of surrogate decision-makers points out significant discrepancies between patients' preferences and their spouses' substituted judgements. Substituted judgement is considered for patients with a life-limiting illness like ESRD whose decision-making capacity is likely to be compromised and, therefore, who want to make sure that their preferences are respected. However, the study found out that spouses' perceptions can differ significantly, meaning spouses use different criteria for decision-making, have a different perception of the patients' conditions or the spouses' own characteristics play an important role for potential discrepancies. Therefore, the study suggests to introduce interventions to help both sides to understand the decision-making process better and to help to reflect more closely the patients' preferences, for example in the form of hypothetical situations. Especially communicating patients' characteristics is recommended to support better surrogate judgement accuracy.



<https://images.vexels.com/media/users/3/138830/isolated/lists/7051b99bbbaad0a73a7c16c7cf9ddca9-couple-family.png>

Walker et al. (2012) conducted a study that investigated the adherence of pre-dialysis CKD-patients to behaviour changes to lower the risk of comorbidities. The authors identified a number of barriers that could potentially compromise behaviour or life style changes: patients do not want to be a burden to others and tend to conceal their condition, balancing violations of dietary restrictions with compensatory strategies, concerns about the side effects and possible harms of medication, but also uncertainties about symptoms and if they are age- or kidney-related. Suggested strategies that could support adherence to regimens positively include **encouraging patients to disclose the nature and impact of their illness, supporting them to make good decisions in difficult circumstances and finally helping patients to get access to practical support from family, friends and health care professionals.**



Integrated health and social care

The question of the assessment and integration of health and social care issues of older people with CKD is in itself fairly extensive and covers a wide range of topics. The complex nature of CKD makes it clear that multi-disciplinarity is essential to deal with all aspects of the disease appropriately.

McKevitt et al.'s (2007) account of findings from the multinational superordinate Dialysis Outcomes and Practice Patterns Study (DOPPS) discusses the implications of the support needs of older people with CKD on haemodialysis (HD) for social care services, for example regarding the increased problem of functional decline and comorbidities, the greater risk of malnutrition or the urgency of end of life issues. **The authors believe that a comprehensive assessment for the planning of social work intervention is crucial and suggest several key areas for further and more refined analysis: social issues, health care and compliance issues, functional status, mental and psychological functioning, legacy/end of life issues.** The discussion introduces interviews, but also screening and assessment tools for physical and mental functioning, depression, and quality of life for an overall in-depth assessment of social care needs. This way social work can be designed to identify goals and maximise the effects of social care interventions.

Wong et al. (2007) and Horigan et al. (2013) discussed CKD on a more general level and looked into health-related effects on the wellbeing of older people with CKD, in these cases the influence of non-dialytic treatment modalities and of fatigue on the quality of life. Wong et al. (2007) focused on factors influencing survival of CKD patients on non-dialytic treatment and stressed the importance of multi-disciplinary teams. One of their main conclusions was that **multidisciplinary teams are vital to help ESRD patients making an informed decision regarding the preferred treatment modality.** Cases of CKD have increased significantly during the last few years and the authors deem it likely that more and more patients will tolerate CKD badly. Multidisciplinary assessment can help maintaining the best possible quality of life. Health and social care should be comprehensive to integrate primary, community and palliative care to allow for the majority of the treatment at home and also consider end of life care, for example to enable a dignified death in the patient's own home.

Horigan et al. (2013) conducted a qualitative study on the effects of fatigue on the wellbeing and quality of life of older people on HD treatment. The authors observed **that fatigue was one of the side effects of dialysis and that it had a strong impact on the daily routine and social life of the patients.** Periods of fatigue limited any kind of activity, but especially how much the participants were able to interact with friends and family. Social care could provide support of developing effective coping mechanisms, for example in areas like maintaining a functioning social life or preventing potential isolation and loneliness due to fatigue. But also identifying appropriate assistance in managing exhausting domestic tasks or the consequences of mental fatigue regarding the handling of an independent life style would be essential for support services. However, further research is needed in the role of the nephrology nurse and how their collaboration can benefit social care.

One of the major health risks for older people with CKD is an increased risk of fall and its related risk of morbidity and mortality. The prevention of avoidable risks will, therefore, be of concern to social care as well. Roberts et al. (2007) and Nitsch et al. (2009) investigated falling and hip fractures, from which social care needs could be extrapolated.



Source: en.wikipedia.org

Roberts et al. (2007) found that older patients on HD have a high incidence of falls, which can also have major consequences in terms of morbidity and mortality. Reasons why older dialysis patients are at particular risk can be cardiovascular disease, autonomic neuropathy, myopathy, polypharmacy, fluid shifts during and after dialysis sessions and depression. **The authors state that falls are often preventable and believe that multi-disciplinary interventions including social care interventions targeted at particular risk factors can reduce the incidence of falls.** However, they also suggested that more research is needed, because there are no specific guidelines for older dialysis patients, but these patients tend to be frailer due to comorbidities, and there are also special treatment factors that may have particular relevance to falls. Therefore, the standard approach to fall prevention might have to be enhanced by additional professionals, which could include the input of a renal social worker to assess such things as housing suitability and adaptability.

Nitsch et al. (2009) were able to establish a connection between CKD at old age and hip fracture-related mortality. They found out that patients with kidney dysfunction and a related estimated glomerular filtration of less than 45 ml/min/1.73 m² (eGFR < 45 ml/min/1.73 m²) have an almost 2-fold increase in hip fracture-related mortality. However, they suggest that many of the mediators in kidney



Source: pmcaregivers.com

disease are treatable and point out that more research is needed on the prevention of falls and the effects of aggressive inpatient management of fracture. Social care could offer support in referrals relevant to fracture treatment and medication management regarding drugs associated with a propensity to fall, but also look into preventive measures like exercise in daily living.

Self-management and implications for social care

Usually, the maintenance of self-management and independence is a decisive aspect in patients' lives and is often closely connected to social care issues. This can include issues such as in-house support for completing home treatment, accessible transportation, having appropriate housing and social support, managing of finances and daily routine, having control over one's life or coping with the effects of mental impairments. Additionally, there is evidence that the NICE criteria for nephrology referral needs to be reviewed as findings show that many patients (2/3) required at least one intervention to assist with CKD management, but only 6% met NICE criteria for nephrology (renal team) referral. Once referred to the renal team, patients should have access to the renal social worker to identify and plan to meet their social care needs.

Prakash et al. (2007) investigated the impact of satellite units for HD treatment in rural areas in Canada. They found out that the satellite units improved access to renal replacement therapy for older patients, but also decreased their travel time. The results suggest that the settlement of treatment centres in rural areas might be effective to provide geographically isolated patients with better access to HD treatment, particularly, if they tend to be less mobile in old age or have less transport facilities than patients in metropolitan areas. Conversely, the development of better transportation for older people with CKD can decrease regional disadvantages in health care provision and improve accessibility to necessary treatment units.



Source: theconversation.com

Namiki et al. (2010) were interested in the self-management of older people with ESRD on home HD. They found out that participants tended to be very positive about self-managing their treatment, because it supported factors like sense of control, independence and a positive sense of self. Besides a high engagement the participants also benefitted from a mutual, active and balanced relationship with their dialysis partners, usually their spouses. Social care services can play an important role in facilitating access to education and organising

the self-management of dialysis treatment, for example facilitate engagement of patients and their partners with health care professionals, but also identifying social care needs of older people in general, but also in the context of specific demands of their illness and treatment. The study highlighted the positive observations on the patient-partner relationship and suggested further research on its effects. Additionally, the need of the inclusion of a participant diversity was noted to gain a better understanding of different experiences and needs.

Cook et al.'s study (2008) deals with functional impairment of older people with CKD on HD. According to their findings, disability in self-care in the form of poor physical performance is very common, e.g. standing up from a chair without support of the arms. **Basic household maintenance tasks were the most common problem, including core activities of daily life like walking, transferring, bathing and clothing.** Polypharmacy, poor mobility performance and low education were identified in the study as predictors for deficits in activities of daily life. But disability in older people on HD still tends to be under investigated or underreported by the patients themselves. That means a greater focus needs to be given to older people on CKD and on their potential impairments and associated social care needs, how this might affect the ability for self-care and what social care can do to assist and monitor older people with a potentially deteriorating condition with basic tasks and activities, especially, if the degree of their functional decline still tends to be underestimated.

The aspect of cognitive decline in CKD patients in old age was investigated by Thornton et al. (2007). They found that, even if participants with other illnesses like dementia or stroke were excluded, older patients still exhibited significantly higher rates of cognitive impairment, for example memory loss and a decline in executive functioning. The authors suggest that **a better understanding of the factors underlying the neuropsychological performance of CKD is crucial for the development of further treatment and the expected cognitive performance.** Cognitive decline can also signal a need for increased social care such as appropriate support for the management of complex medication regimens and dietary requirements.

Rifkin et al. (2010) looked at the self-management of older CKD-patients and their medication adherence, who were taking only non-transplant medication at the time of the study. Apart from physical, logistic or financial barriers to adherence the participants described a lot of non-medical reasons that motivated their non-adherence to their prescribed medication regimen. For example, major reasons for non-compliance were the weighing of possible side-effects and the risks of polypharmacy against the benefits of medications, alleged asymptomatic or low-priority diseases or the assumed influence of marketing on the prescription decisions by their physicians. The study suggests that poor health literacy/education as well as a lack of

consideration of patients' priorities and concerns are major reason for patients' decision-making, but also still more research needs to be done to fully understand the different factors that influence adherence. **Social care services are frequently introduced to support medication taking when insufficient adherence affects the person's renal health and wellbeing.**

Axelsson et al. (2012) looked at the experiences of older patients on HD at the end of life and focused particularly on the emotional and psychological aspects of being severely ill. The

study comes to the conclusion that **the feeling of a loss of control and increasing dependence on others, the effects of suffering and a deteriorating aging body on one's self and on social life had negative impact on older patients. This is something that social care practitioners should be aware of when dealing with older patients at the end of life and develop strategies that address their needs to maintain a sense of self, feel being listened to, be accepted and respected and, as mentioned in the study, a need for physical interaction as expressed by study participants.**



Renal diets and implications for social care

Some studies generally reported **participants were not complying with their renal diets (for example Aasen et al. 2012), even though they had been warned how vital their diet was. Findings also show that the feeling of lack of control results in patients making dangerous decisions with diet and attempting to hide their condition.** Two studies focused on dietary requirements for patients with CKD, which have implications for social care. Johannsson et al. (2013) investigated the influence of psychosocial factors and potential effects for social care, while Campbell et al. (2008) looked into potential positive effects of a structured nutrition intervention at home.

Johannsson et al. (2013) compared older patients on HD and PD with a comparable demographic regarding differences in nutrition intake. The study found out that the dialysis mode did not have a significant impact, however, instead, psychosocial factors had a noticeable influence on protein and energy levels. According to their findings **higher energy protein intake was independently associated with higher social network score, better subjective physical quality of life, absence of depression and better socio-economic Index of Deprivation score.** Therefore, social care that aims to improve nutritional intake should focus explicitly on factors that refer to these issues in terms of improving psychological and physical wellbeing, for example in the support of an adequate and positive social network, but also take into account socio-economic factors that can have a potentially negative effect on patients' nutritional goals. However, the study suggests a further interventional study to explore, whether increasing social support or identifying and treating depression can reduce Protein Energy Waste (PEW) or raise the quality of life.

Campbell et al. (2008) dealt with increasing malnutrition in pre-dialysis patients and possible positive effects of nutrition intervention. They found out that individualized dietary counselling with regular follow-up might contribute to positive outcomes regarding body composition and nutrition intake. But there were strong differences regarding gender, meaning that especially female participants benefitted from the intervention while male participants showed little response in general. Particularly regarding older participants, gender differences were significant. In terms of the self-management aspects of the intervention, female participants showed a much stronger orientation towards health care needs and behavioural change, while older male participants relied more on chance or other factors to instigate change than themselves. To conclude, social care, that aims to support more self-management and control for older people, needs to take into consideration gender-dependent differences in behaviour and socialisation as a contributing factor. The study suggests that **structured dietetic care might be beneficial, but potential gender differences in response to treatment require further investigation.**

Relationships with care providers

Some patients would often play down their symptoms to their health care professionals (Aasen et al. 2012), to regain some control of the situation and to avoid going to hospital. There are also conflicting findings, with some studies (Namiki 2010), concluding that the participants claimed they had strong relationships with health care professionals, considering them 'family' and could turn to them for education/support, whilst others such as Aasen et al. 2012, described how older people referred to health care professionals as 'jailers'. Participants were found to be almost in a power struggle with their health care professionals and with the illness themselves. However, there is evidence (Namiki et al. 2010), that **a positive relationship with health care professionals can be linked to a more positive experience of self-management.** Further studies (Axelsson et al. 2015), describe how relatives of those with CKD feel that the support and level of communication with the health care team is crucial.

Social care as a neglected element of end of life care

Two studies looked at end of life care and CKD (Cohen et al. 2010 and Murtagh et al. 2010, 2011). Findings show that the pattern of decline in the end stages of life is different than that with other illnesses, therefore, end of life care plans need to be developed to support those during their final weeks of life (Murtagh et al. 2011).

Murtagh et al. (2011) explored the functional decline in the last year of life of end-stage renal disease patients on conservative management without dialysis. Patients' needs change dramatically and fast in the last months of life and this includes their social care needs. **This rapid functional decline requires close monitoring to identify suitable support (for example increased need for help with (self-) care or assistance with domestic tasks (for patients living at home) and personal assistance with factors due to cognitive decline e.g. with medication adherence, hygiene and diet management).**

Murtagh et al. (2010) subsequently analysed symptoms of kidney disease in the last month of life and identified a clear need for social care and support as well as medical intervention to palliate symptoms. People experienced an average of 20 unpleasant symptoms. Some symptoms that caused a lot of distress according to patients' reports were common (lack of energy, itch, drowsiness, dyspnoea, poor concentration, and pain). Psychological symptoms like worrying or feeling sad, nervous or irritable also affected the patients' wellbeing. Additional social support for families as well as the patients during this demanding phase can also help mitigate the challenges faced at end of life.

Having identified that older people with kidney disease have a high symptom burden at the end of life with increased need for social care, current referral rates to hospices are low and not all hospices accept people with a non-cancer diagnosis. **Hospice services integrate health and social care at the end of life and people with CKD miss out on the holistic care provided by hospices and palliative care services, if they are ineligible or unable to access the service.** Cohen et al. (2010) tested an intervention to increase referral rates to hospice care in a randomised controlled trial. They identified a lack of acceptance of death by people with CKD, and a lack of information on the option of hospice care from the nephrology professionals that prevented optimal referral. The findings also suggest that patients and their families benefitted from regular educational and psychological counselling in order to access hospice care at the appropriate time. In this context regular contact with nephrology staff was vital to promote reassurance for patients' and their families as well as the smooth organisation for the referral process. More people who received the supportive educational intervention were successfully referred to hospice care. These findings suggest that psychological support or even therapeutic options should be provided to support patients (and their families) to be able to deal with the emotional and psychological strain of increasing physical and psychological deterioration due to effects of the progressive terminal illness.



Source: flickr.com

Terminal care support e.g. grief counselling for patients and families would be beneficial at the end of life. The evaluation of appropriate care for patients with a rapidly changing condition (which can include social care services) on how to accommodate dying patients in a demanding situation as well as related issues can require the need for additional support. For example, administrative or financial aspects associated with patient care and death.

These studies had a clear medical perspective with statistical methods as the main (sometimes only) data source. The nuances of the patient and family perspective is difficult to capture from these approaches (Cohen et al. 2010). There is still a lack of insight into the effects of functional deterioration of patients with end-stage-renal-disease (ESRD) in terms of appropriate disease management and palliative care (Murtagh et al. 2010). The small sample sizes, the nature of the different degrees of functional decline, and the varying needs of individual support needs further investigation to better understand the associated care needs and the consequences of further treatment (Murtagh et al. 2011).

Advance Care Planning (ACP)

Closely related to end of life care is a study published by Anderson et al. (2006) on Advance Care Planning (ACP). ACPs are supposed to establish and document the treatment and social care preferences of patients with ESRD who are dependent on life-sustaining-treatment like dialysis. However, the study



found out that only a minority of ESRD patients or their families use ACPs to formulate their wishes, although many older patients with severe ESRD express their wish to not attempt resuscitation when doing an ACP. This suggests that patients, potential surrogate decision-makers, and their families still need more education and opportunities to use ACP. Accompanying terminal-care-counselling and social support services can help to identify personal values and goals decisive for further treatment as well as ensure their implementation, especially regarding sensitive treatment decisions, when patients might become unable to make these decisions themselves. Finding suitable individual approaches, for example discussions and face-to-face-contact, also needs to be considered to create better accessibility for families to ACPs. Bristowe et al. (2014), however, concluded that health care professionals are not equipped to deal with discussions with deteriorating patients with ESRD about their future and care plan needs.

Many participants wished that they had been able to discuss end of life with their relatives, however, when they tried to do so, they were quickly brushed off (Axelsson et al. 2012). A further study (Axelsson et al. 2015) found that after the older person had passed on, the relatives wished they had been able to discuss end of life with them. This finding suggests that perhaps targeted counselling could be beneficial for both the patient and their families as they approach end of life. Additionally, there is clear evidence that relatives feel left out in decision-making. It is important that relative care givers are included as much as possible in the information and care plans as the review has also told us that patients can conceal symptoms and not adhere to diet etc. If a relative care giver is kept up-to-date on the progress of the illness, they could be more equipped to pick up on these issues.



WHAT DOES THIS MEAN?

➡ **There is an incomplete picture of the social care needs of older people with kidney disease**

Social care needs are very individual, can be very wide ranging and increase over time. Renal clinicians confirm that they are coming into contact with greater numbers of older people with CKD who often develop multiple comorbidities, e.g. limited mobility and a decline in the basic activities of daily life (Gopinath et al. 2013). CKD is a long-term condition and the incurable nature of the disease means that people living with it (and especially those requiring dialysis) have a deteriorating quality of life including limitations in functional independence resulting in restricted social participation (Guerini et al. 2006).

➡ **Lack of social care interventions at the appropriate time is an important factor that affects health outcomes and quality of life**

For example, the sedentary and isolating lifestyles experienced by many older people with kidney disease and flagged by their clinicians leads to an increase in social care needs and puts greater demand on social support services. Many older people with kidney disease appear to end up in residential care due to lack of in-home social care options. Conversely, an increasing use of social support services in the community can have positive effects, older people can stay longer in their homes, in their communities, and the admission to residential care can be delayed. For many older people continuing personal independence is associated with better quality of life and can reduce the need for and cost of residential care (Gopinath et al. 2013).

➡ **Studies led by social care professionals are few, and there is a general lack of evidence to inform social care practice**

There appears to be no evidence to inform specific areas of social care for those with CKD, such as housing, cooking, exercise, isolation, finances, welfare benefits, transport, holidays and respite, which is a surprising finding as many of these gaps in research are likely playing a significant part in the lives of older people with CKD. There were no studies on employment, however, it could be argued that as the inclusion criteria was for studies of those aged 65 and over, employment is potentially less of an issue.

➡ **Lack of diverse methods and non-medical perspectives in studies**

We identified few qualitative studies and none that reported key stakeholder perspectives on accessing and receiving social services. Data has been gathered through methods such as surveys etc., however, it is difficult to grasp how a patient truly feels about their condition or their services without giving them the opportunity to tell their story. There is a lack of longitudinal studies and a lack of large sample sizes which make it difficult to generalize the results. Studies conducted in the UK are sparse. Thirteen out of 23 studies in this review were undertaken in the UK. As health care services can vary considerably in different countries, it is important that an adequate amount of studies are generalisable to the UK to inform decision-making.

IMPLICATIONS FOR HEALTH AND SOCIAL CARE ORGANISATIONS

Greater integration of health and social care : needs to occur in a meaningful way to benefit patients.

An increasing number of older people will be living with CKD. Sustainable services are required to meet their health and social care needs.

Health and social care professionals could benefit from improving their skills in conveying information to patients clearly and effectively. Patients and their families could benefit by making the best possible informed decisions for their health and social care plans from a better understanding of the condition and adequate information. Currently important decisions are based on little information or information that they do not fully understand.

FURTHER RESEARCH

There is currently a very small evidence base to inform social care decision-making and the effective integration of renal health and social care. We identified no studies of the effects of social care-led interventions and no studies documenting the experiences of receiving or delivering social care. There are large gaps in the currently superficial understanding of the social care needs of older people with CKD. Social care of older people with CKD needs to be researched in greater depth.

LIMITATIONS

There are several limitations to this review. Firstly, we were only able to include studies in English, therefore we have potentially missed a substantial amount of evidence. Furthermore, there were a small number of studies that we were unable to access due to time/budget constrictions.

We did not include grey literature such as local policies and practice guidelines that may have helped with the identification of social care needs. There was a dearth of studies conducted from a social care perspective, so we had to build a picture of social care needs by looking at health-focussed evidence. Included studies were highly diverse and so the level of synthesis is low.

Further research is needed to compare the dialysis pathway to the conservative management pathway for patients with similar issues (including social care issues) to discover which pathway works better for specific patients. Further research should be conducted to inform interventions to enhance older people with CKDs independence and self-management skills. Additional evidence-based interventions are needed to educate those with CKD and those without CKD to be able to recognise the symptoms and the positive impacts that treatment and additional social care support can bring. Interventions need to be developed to assist people with taking 'control' over their illness and their lives. It is also clear that new studies conducted into end of life care need to use data collected over longer periods of time.

CONCLUSION

This is the first review exploring the social care needs of older people with kidney disease. We hope that findings will stimulate the production of new research to fill the many obvious gaps.



Source: theconversation.com

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APPENDIX 1

Search Strategy

Free text searches :

1. ((kidney* or renal or transplant* or daily* or *dialysis) AND (“older people” or “older adult*” or “older women” or “older men” or age* or aging or elder*) AND (social or socio* or psychosocial or support or “daily living” or services))
2. ((kidney* or renal or transplant* or daily* or *dialysis) AND (“older people” or “older adult*” or “older women” or “older men” or age* or aging or elder*) AND ((community or neighbour* or home) adj3 (contact or support or care*))
3. ((kidney* or renal or transplant* or daily* or *dialysis) AND (“older people” or “older adult*” or “older women” or “older men” or age* or aging or elder*) AND survey)

Index search:

Use of any available index terms for social support, care or services (map to social or community)

Hand searching:

The following journal was hand searched:
The Journal of Nephrology and Social Work

APPENDIX 2

Table 1 Summary of included studies

Authors	Publication Date	Study Design	Aim	Sample	Key Findings
Aasen, E. A., Marit Kvangarsnes, M., Heggen, K.	2011a	Qualitative study	To explore how elderly patients with end-stage renal disease (ESRD) who undergo treatment with haemodialysis (HD) perceive patient participation in a dialysis unit	11 patients on treatment with HD for more than 2 months, over 70 years old, and without transplantation	2 dominant discursive practices: the health care team's power and dominance and the patients' struggle for shared decision-making.
Aasen, E. M., Kvangarsnes, M., Wold, B., Heggen, K.	2011b	Qualitative study	To explore how family members perceive participation in HD treatment of competent older people	7 family members	3 discursive practices detected: to care and take control (between next of kin and patients); to struggle for involvement, and to be forgotten and powerless (interaction with health care team)
Anderson, J. E., Sikorski, I., Finucane, T. E.	2006	Case-control study	To explore factors influencing advanced care planning and the effect of plans on outcome	109 continuous ambulatory PD patients admitted during a 10-year period to a single academic-affiliated nursing home	ACP is important, because dialysis patients often face severe illness and incapacity, but age and functional status strongly influence DNAR and DNH plans.
Axelsson, L, Randers, I., Jacobson, S. H., Klang, B.	2012	Qualitative study	To describe and to elucidate the meanings of being severely ill living with HD when nearing end of life	8 purposefully selected, severely ill adults with ESRD	Meanings of being severely ill and living with HD at end of life emerged as living with suffering simultaneously with reconciliation and wellbeing.
Axelsson, L., Klang, B., Lundh Hagelin, C., Jacobson, S. H., Andreassen Gleissman, S.	2015	Qualitative study	To describe and elucidate the meanings of being a close relative of a severely ill family member treated with maintenance HD approaching the end of life	14 close relatives	Findings show that with increasing demands, support from health care professionals increasingly significant. Collaboration and being acknowledged strengthened relatives, while lack of support expressed as feeling alone and abandoned
Barrett Bowling, C., Patricia Sawyer, Campbell, R.C., Ahmed, A., Allman, R.M.	2011	Cohort study	To examine the longitudinal association between CKD and the decline of IADLs and BADLs among community-dwelling older adults	Sample of 357 community-dwelling older African American and white Medicare beneficiaries	Study suggests that in community-dwelling older adults CKD predicts future decline in both IADLs and BADLs. Importance of severity of CKD stage for predicting functional decline

Bristowe, K., Shepherd, K., Bryan, L., Brown, H., Carey, I., Matthews, B., O'Donoghue, D., Vinen, K., Murtagh, F. EM	2014	Cohort study	To develop and pilot a Renal specific Advanced Communication Training (REACT) programme to address the needs of end-stage kidney disease (ESKD) patients and renal professionals	16 participants (9 renal nurses/ health care assistants and 7 renal consultants) in two UK teaching hospitals	Study investigated implementation of REACT -programme: need to improve end of life care for ESRD patients, to enable them to make informed decisions about future care. Challenges include prioritising communication training among service providers
Campbell, K. L., Ash, S. Davies, P. SW., Bauer, J. D.	2008	Randomised control trial	Intervention group provided with individualized dietary counselling with regular follow-up, aimed at achieving an intake of 0.8-1.0g/kg protein and >125kJ/kg energy; or control, receiving written material only. Outcomes: Body composition, nutritional status and dietary intake	56 (Male 62%; age mean (SD) 70.7 (14.0) years) CKD outpatients, randomly allocated to intervention (n=29) or control (n=27)	Structured nutrition intervention may provide beneficial patient outcomes including limiting deterioration in nutritional status and increasing dietary energy intake when compared with control treatment for patients in pre-dialysis. Impact of such interventions on body composition needs to be investigated further
Carson, R. C., Juszczak, M., Davenport, A., Burns, A.	2009	Cohort study	To compare clinical outcomes for patients who had ESRD and chose either MCM or renal replacement therapy (RRT)	202 elderly (>70 yr) patients who had ESRD and had chosen either MCM (n 29) or RRT (n 173)	Elderly patients with ESRD + comorbidity have 2 years longer survival with dialysis; patients with MCM can survive substantially, achieving similar numbers of hospital-free days to HD patients
Cook, WL, Jas-sal, SV	2008	Mixed-method study	To identify clinical characteristics of older HD patients who need help with day-to-day activities	162 patients aged 65 years or more and on chronic in-centre HD	Disability in self-care common among older patients on HD. Strategies needed to identify older dialysis patients at risk of functional impairment and to limit their disabilities
Rifkin, D. E., Barton Laws, M., Rao, M., Ba-lakrishnan, V. S., Sarnak, M. J., Wilson, I. B.	2010	Qualitative study	To find out how older patients with CKD prioritize their medical conditions or decide which medications to take	20 participants (age range, 55–84 years; mean, 72) with CKD stages 3-5D	Polypharmacy lead to complex medication choices and adherence behaviours. Most of interviewed patients had beliefs or priorities non-concordant with conventional medical opinion; rarely discussed with physicians

Harwood, L., Wilson, B., Locking-Cusolito, H., Sontrop, J., Spittal, J.	2009	Questionnaire study	To provide an overview of valid and reliable instrument used to measure stressors of patients with CKD, identify those stressors, and determine which coping strategies were used and effective in the study	226 individuals with CKD not on dialysis	Authors developed and tested reliable and valid instrument; In terms of coping strategies, optimism was used most frequently and considered most effective among this patient population
Horigan, A. E., Schneider, S. M., Docherty, S., Barroso, J.	2013	Qualitative study	To provide an overview of fatigue and self-management of fatigue for patients on HD	14 adult patients on in-centre HD	Participants reported feeling "washed out" and "drained" physically and reported mental fatigue
Johansson, L., Hickson, M., Brown, E. A.	2013	Observational study	To explore relationship between nutritional parameters and psychosocial factors in older people on dialysis	106 patients 65 years of age or older and on dialysis for at least 90 days	Evidence that higher energy and protein intake in older people on PD and HD is significantly and independently associated with following psychosocial factors: higher social network score, better subjective physical QOL, absence of depression, better IoD scores
Li, M., Porter, E., Lam, R., Jassal, S. V.	2007	Quality improvement report	Addressing challenges that provision of rehabilitation with the aim of restoring personal independence in elderly HD patients faces	164 patients admitted to integrated dialysis rehabilitation service from 8 secondary or tertiary care nephrology units, 15 patients (9.1%) admitted from home, the remaining patients admitted from acute care institutions	Data suggest geriatric rehabilitation is feasible for older HD patients after acute care hospitalization or acute loss of function, and substantial proportion of patients can return to their homes
Llewellyn, H., Low, J., Smith, G., Hopkins, K., Burns, A., Jones, L.	2014	Qualitative study	Drawing on a phenomenological approach, focus was particularly on embodied and lived experience of the condition and on how participants constructed treatment modalities and approached treatment choice	12 men and 7 women who represented spectrum of older age (73 to 94 years) and were diverse with regard to illness severity, cultural background, education, previous professional experience.	Findings suggest that people see their illness differently at different time-points during illness, that illness experience is largely constituted in practice and language of medicine and how particular treatments can contribute a potential for disruption more than illness itself.

Cohen, L. M., Ruthazer, R., Germain, M. J.	2010	Cohort study	To evaluate an intervention to facilitate hospice referral	133 participants (82 intervention and 51 control) with indicators of poor prognoses	At conclusion of study, hospice services had increased at intervention sites, subgroup of 65-year-old subjects had undergone significant increase in obtaining hospice care
Maaroufi, A., Fafin, C., Mougél, S., Favre, G., Seitz-Polski, B., Jeribi, A., Vido, S., Dewisme, C., Albano, L., Esnault, V., Moranne, O.	2013	Cohort study	To report patients' preferred treatment options for ESRD after information delivery, patients' characteristics by treatment preference, and reasons for differences between treatment preference and treatment delivered	228 patients in nephrology department with CKD and incident dialysis patients who received information programme about ESRD treatment options	Study suggests to inform patients systematically before starting dialysis, to take their preferences into account before organising dialysis and to make all treatment modalities available in all centres
McKevitt, P., Bommer, J., Bragg-Gresham, J. L., Pisoni, R. L., Keen, M. L., Lopez, A. A., Andreucci, V. E., Marumo, F., Akiba, T., Akizawa, T., Port, F. K.	2007	Mixed-method study	To provide a wide range of data on a sample of people on HD randomly selected from nationally representative samples of dialysis facilities in 12 countries	Sample of HD patients randomly selected from nationally representative dialysis facility samples in 7 countries from 1996 to 2001, and 12 countries since 2002	Older patients face increased comorbidities; decreased functional status, changes, loss associated with aging; increased mortality rates. Managing medical, dialysis treatment, nutritional, psychosocial needs and problems challenge members of dialysis treatment team
Moustakas, J., Bennett, P. N., Tranter, S.	2015	Qualitative study	To explore the information needs of older people with ACKD who choose supportive care as treatment	6 participants with supportive care between 73 and 87 years old, consisting of 4 males and 2 females	Study confirmed gaps in supportive care information provision when there is no formal renal supportive care programme
Murtagh, F.E., Addington-Hall, J., Edmonds, P., Donohoe, P., Carey, I., Jenkins, K., Higginson, I. J.	2010	Cohort study	To determine symptom prevalence and severity in the last month of life for patients with Stage 5 CKD, managed without dialysis	74 patients with Stage 5 CKD being managed conservatively (without dialysis)	Stage 5 CKD patients have clinically important physical and psychological symptom burdens in the last month of life, similar or greater than those in advanced cancer patients; this must be addressed accordingly
Murtagh, F. E. M., Addington-Hall, J. M., Higginson, I. J.	2011	Cohort study	To determine the functional trajectory in the last year of life in ESRD managed without dialysis	74 participants with Stage 5 CKD being managed conservatively (without dialysis)	Study demonstrates that functional status of patients with conservatively managed ESRD is maintained until late stage of illness, with more rapid decline toward death than described for other conditions; leads to clinical implications for health care

Namiki, S., Rowe, J., Cooke, M.	2010	Qualitative study	To understand challenges older people living with ESKD and home HD face in their every- day life	4 partici- pants aged between 60– 75 years, with ESKD and current- ly enrolled in programme of home HD	Findings indicated transformed care dy- namic, positive apprais- al and active everyday engagement by partici- pants. Positive outlook on life enabled partici- pants to look to their future with purpose and hope. Outstanding sys- tems of partnership sig- nificantly facilitated this view
Nitsch, D., Mylne, A., Ro- derick, P. J., Smeeth, L., Hubbard, R., Fletcher, A.	2009	Cohort study	To examine whether CKD at older ages is associated with hip fracture- related mortality	Participants were pa- tients aged 75 and over, registered in 106 general practices se- lected from the MRC General Practice Re- search Framework and selected to be repre- sentative of the UK gen- eral practice standardized mortality ratios (SMRs) + Jarman dep- rivation score; 15,336 sub- jects attend- ed for base- line assess- ment in uni- versal arm	Even after adjusting for confounding factors, study finds that amongst those with eGFR < 45 ml/min/1.73 m ² , a substantive pro- portion of hip fracture- related deaths appeared to be related to the kid- ney dysfunction itself
Nitsch, D., Mann, A. G., Bullpitt, C., Ro- derick, P. J., Fletcher, A.	2011	Cohort study	To assess the association of kidney function with quality-of- life in communi- ty-dwelling old- er adults aged 75 years or more in the UK	3,211 partici- pants aged over 75 years from 106 practi- ces who un- derwent baseline as- sessment and who had QOL data	Lower eGFR is associat- ed with dimensions of poorer QOL at older age in both men and wom- en; men with eGFR <45 reported poorer morale, women with eGFR <45 reported more problems with body care
McIntyre, N.J., Fluck, R., McIn- tyre, C., Taal, M.	2012	Cohort study	To assess treat- ment needs of CKD stage 3 pa- tients in primary care, as well as their awareness of CKD	1741 partici- pants under- went clinical assessment including urine and blood tests, participants were asked about awareness of their CKD	Two-thirds of patients with CKD stage 3 on GP registers required at least one intervention to improve their manage- ment; 41% of partici- pants unaware of CKD diagnosis, despite being on CKD register

Oliver, M. J., Garg, A. X., Blake, P. G., Johnson, J. F., Verrelli, M., Zacharias, J. M., Pandeya, S., Quinn, R. R.	2010	Cohort study	To determine the impact that contraindications and barriers to self-care have on incident PD use, and to determine whether family support increased PD utilization when home care support is available	497 incident ESRD patients assessed	Even when home care assistance for PD available, family support important driver of PD eligibility, choice and use among patients with barriers to self-care PD
Prakash, S., Austin, P. C., Oliver, M. J., Garg, A. X., Blake, P. G., Hux, J. E.	2007	Cohort study	To consider whether constructing satellite HD units in rural regions of Ontario, Canada, alleviated under-service of rates of RRT locally, decreased patient travel distance and decreased local PD utilization	Unit of analysis for study was geographic region; two groups of rural regions at two time periods compared	Building satellite units effective approach to HD delivery since they improved access to RRT for elderly patients, decreased travel time for patients on HD and did not create supply-induced demand for RRT
Pruchno, R. A., Lemay, E. P., Feild, L., Levinsky, N. G.	2006	Qualitative study	To examine factors predicting preferences for continued HD treatment among patients with ESRD and to compare these factors to those predicting their spouses' predictions of patients' preferences	Total of 291 HD patients, aged 55 years and older, and their spouses	Patients and surrogates used different criteria when judging continuation of life-sustaining treatment, patients' condition perceived differently. Substituted judgments of spouses influenced by their own characteristics; explains inaccuracies in judgments
Rantanen, M., Kallio, T., Johansson, K., Salanterä, S., Virtanen, H., Leino-Kilpi, H.	2008	Questionnaire study	To increase awareness about the knowledge expectations held by patients receiving dialysis treatments	47 patients receiving dialysis treatment in hospital	Retired patients expected more knowledge about experiential dimension such as who to talk with about feelings concerning illness. Study suggests more conversational therapy for retired patients.
Roberts, R., Jeffrey, C., Carlisle, G., Brierley, E.	2007	Mixed-method study	To see if centre HD patients reported falls, syncope, pre-syncope or dizziness	78 patients	Older HD patients have high incidence of falls. Falls can be prevented by addressing modifiable risk factors.

Thornton, W. L., Shapiro, R. J., Deria, S., Gelb, S., Hill, A.	2007	Case-control study	To compare aspects of verbal memory and executive functioning in 51 community-dwelling persons with chronic kidney disease (CKD) and 55 healthy controls matched on age and education.	51 CKD and 55 control participants	Older CKD participants exhibited worse performance than matched controls on all aspects of memory and executive functioning assessed. Examination of the effect size estimates indicates that the magnitude of the cognitive differences observed is moderate to large with very large differences noted in verbal memory in older CKD participants
Tonkin-Crine, S., Okamoto, I., Leydon, G. M., Murtagh, F. E. M., Farrington, K., Caskey, F., Rayner, H., Roderick, P.	2015	Qualitative study	To explore patients' reasons for choosing conservative management and to compare the views of those who have chosen different treatments across renal units	Patients 75 years or older recruited from 9 renal units	Divide between conservative management and dialysis/pre-dialysis patients in whether to expect they would live longer on dialysis therapy and whether quality of life would get better or worse. These beliefs appeared to be influenced by the information provided by renal staff, particularly whether patients were aware of conservative management as an option
Visser, A., Dijkstra, G. J., Kuiper, D., de Jong, P. E., Franssen, C. F. M., Gansevoort, R.T., Izaks, G. J., Jager, K. J., Reijneveld, S. A.	2009	Qualitative study	To explore considerations taken into account by these patients in decision-making regarding renal replacement therapy	14 patients aged 65 years or older	Patients' decisions to decline or accept dialysis are not based on effectiveness of treatment, but rather on personal values, beliefs and feelings toward life, suffering and death, and expected difficulties in fitting the treatment into their life
Walker, R., James, H., Burns, A.,	2012	Qualitative study	To explore the experiences of patients attempting to integrate life-style changes into their lives	9 patients with CKD Stage 4	Practical support from family and health care professionals, willingness to disclose their condition and help to make good decisions in difficult circumstances were identified as important factors with behaviour change.
Wong, C.F., McCarthy, M., Howse, M.L.P., Williams, P.S.	2007	Cohort study	To explore prognosis of non-dialytic treatment patients in terms of hospitalization rates and survival	73 non-dialytic treatment patients	Likely to be increasing number of elderly patients who will tolerate dialysis badly. Study suggests multidisciplinary approach to assist ESRD patients in choosing their modality of RRT, with agreed care plan to manage chosen modality to achieve best possible quality of life.